Minutes AGM
OIFE General Assembly 2023

Date: June 10th 2023
Time: 16.30 – 18.00 CET
Place: Scandic Continental Hotel, Stockholm

See attached full list of delegates present.

OIFE Board Members:

1. Ingunn Westerheim - President
2. Bruno Van Dijk – Vice President
3. Coreen Kelday - Treasurer
4. Anna Rossi - Communications
5. Malene Sillas – Board Member (voting for DK)
6. Stephanie Claeys – Board Member

Individual members present with voting rights:

7. Austria: Eva Sacherer
8. Belgium: Lieve Michiels
9. Denmark: Malene Sillas
10. Finland: Anita Ojanotko
11. France: Benedicte Alliot
12. Germany: Andrea Kiel
13. Italy: Simona Paveri
14. Latvia: Dace Liepina
15. Norway: Inger-Margrethe Stavdal Paulsen
16. Sweden: Inger-Margarethe Stavdal Paulsen (proxy vote)
17. Portugal: Fátima Godinho
18. Spain: Julia Piniella
19. Switzerland: Therese Stutz Steiger
20. The Netherlands: Taco van Welzenis
21. UK and Ireland: Penny Clapcott

Welcome & opening remarks given by IW

House keeping & formalities

- Practical information & voting rules were explained by IW
- Election of meeting volunteers: Inger-Margrethe Stavdal Paulsen approved as Chair of meeting, Ute Wallentin and Coreen Kelday to act as secretaries and Eva Sacherer and Willemein to count votes.
- Counting of votes – 14 countries present with voting rights.

Settlement of agenda – approved by all

Approval of annual report

In April 2022 OIFE moved its formal registration from the Netherlands to Belgium. Between March and October 2022, assets & liabilities were transferred to the new legal entity in Belgium. OIFE in the Netherlands was officially dissolved October 1st 2022. The Annual Report for 2022, therefore applies to both OIFE Netherlands and OIFE Belgium

Highlights and updates were provided on various topics:

Volunteers of the OIFE

Online events hosted by OIFE
- Leadership meeting
- Establishing meeting
- AGM & educational webinar (moved from Valencia)
- Extraordinary GM
- OIFE Investigator Meeting (80 new contacts)

Face to face events where OIFE was represented
- ICCBH conference in Dublin
- GEMSTONE meeting in Rotterdam
- OI2022 in Sheffield (the whole Board)
- iCan course for children in Lyon
- Brussels International Forum

- OIFE Youth Event in Belgium (event in Poland cancelled)
- 2 new member organisations – Canada and Kazakhstan
- More companies researching OI
- Patient involvement
- Future therapies
- Grants and donations for OIFE

Updates were given on:
- the Impact Survey
- Pain and OI Project
- Advocacy and policy work (most through EURORDIS)
- Communications and Awareness raising campaigns (including 3 OIFE magazines)
- Research
- Peer Work

Positive Developments for 2022 highlighted were:
- Lots of new requests for collaboration indicated increased visibility as the OI umbrella organisation.
- More interest in research on OI – especially from industry
- OIFE Investigator Meeting was a success and brought us lots of new contacts.
- The Pain and OI project was kicked off with 4 constructive workshops in 2022
- Our knowledge about unmet needs of people with OI increased (for instance through IMPACT). This will be documented and systematized in 2023/24.
- We opened new bank and PayPal accounts – registered in Belgium
- Received an increase in grants and donations from industry, which makes it possible to buy services.

Challenges noted were:

It's increasingly difficult to get feedback from OIFE representatives

- OIFE has different target groups with very different needs (researchers, industry, PAOs)
- Reaching interested people through social media (especially Facebook) is increasingly difficult due to changing algorithms.
- The moving process to Belgium took a lot of time and resources
- Tax rules, accounting and our need for legal advice (formal or pro bono) were not completely settled/clarified
- We temporarily lost our opportunity to do Facebook fundraisers due to change from Netherlands to Belgium
- Decrease in donations and grants from other sources – made us move closer to the 50% limit of pharma funding.
- Documenting in kind hours takes time and resources, but is a necessity
- Companies all work in different ways when it comes to patient involvement and processing of funding applications.
- We did not have time to create a new long-term strategy.

No questions or comments, but appraisal for the excellent work by several participants.

Approval of OIFE's Annual Report 2022

The annual report was approved unanimously.

Approval of financial report & budget

- CK explained that the accounts which were distributed prior to the AGM were not the official accounts.
- The accounts were also for OIFE Belgium only, therefore covering March 2022 to Dec 2022 (not a full 12 month period).
- Accounts process is different to previous years due to OIFE now being registered in Belgium.
- The accounts were sent to SBB (accounts company) who have reviewed and finalized the accounts as per Belgium regulations - therefore no need for a Finance sub committee as per previous years.

Main differences between the accounts which were circulated and the accounts which need approving are (paper copies circulated and also shown on screen):

1. The carried forward balance from OIFE 1 (transferred income from the German bank account) appears as an income.
2. SBB have moved any income in relation to Balancing Life with OI Conference to 2023.
3. Volunteer hours are not reflected in the official accounts (this can be added on to spreadsheets and recorded separately).
4. Belgium accounting systems have official nominal codes for allocating income and expenditure which must be used.

Overall – healthy bank balance with €157,635.24 being the total cash in bank as at 31 Dec 2022.

And €154,026.02 being declared operating profit.

- **Approval of financial report 2022**
  Taco commented on the more difficult looking report compared and CK agreed. Two questions on details were answered. Inger-Margarethe asked for votes and the financial report was unanimously approved.

Budget 2024

CK updated on suggested Budget for 2024
Budget needs to be approved by General Assembly.
Difficult to Board to forecast what projects will come over way over the next 18 months
Therefore included a 30,000 flexible income/expenditure for unforeseen circumstances. A question concerning the deciding factors for the location of the conference was replied to. Simona Paveri asked for the professional services.

- Upon request for approval of budget for 2024 it was unanimously approved.

Elections and appointment of volunteers

- Re-election of OIFE president
  IW is available for another 4 years – unanimous approval and applause
- Election of Board member – Jacob Wittorf – for 4 years
  Jacob briefly presented himself – unanimous approval and applause

OIFE long term strategy (2023 – 2028)

IW gave an overview over the vision and mission and of 6 main goals of OIFE for the next 5 years. These are:

1. Increase Awareness of OI.
2. Empower and educate the OI Community
3. Advocate for the OI community at European level
4. Grow an international network of healthcare professionals and researchers
5. Encourage advancements into Research and Treatments and
6. promote patient involvement on different levels and areas

DM asked for more details about the plans how to encourage advancement in research and IW replied that OIFE is not going to run its own research projects. A question of TSS for relations to other rare bone disorders was replied to as this being part of OIFE's networking.
VOTE to ensure all are happy with these objectives being the main OIFE aims and the board finalizing the long term strategy – unanimous approval.

Final announcements

IW informed about the latest new OIFE supporting member, CLAN, as of this week and an introduction video was shown to the audience.

IW did some final organizational remarks and closed the meeting with a short outlook on the last evening together. She thanked everybody for coming. AR explained that she would like to do short videos about the question what the OIFE does mean to those who would like to participate.
The moderator wished a nice evening.

Minutes taken by Ute Walentin

Signed by OIFE Board